

Introduction and Background

Assembly Member Beall, thank you, I am honored to be invited to speak before this Hearing. I am the Maternal Child and Adolescent Health Director from San Luis Obispo County and the current President of California Maternal Child and Adolescent Health Action. I have been a Public Health Nurse for the past 23 years and have had the privilege to work with women, children and their families concerning health issues and access to care.

I am here today, not only as the MCAH Action President, but as a mother of an adoptive son who has Fetal Alcohol Syndrome (FAS). My son is now 14 years old and in the 8th grade. We became involved in his life when he was 2 ½ months old. His birth mother was living in a car with her 3 children with no help in sight. We initially took Michael so that his mother could find a place to live. We had him off and on until around 11 months of age, when his mother decided that she wanted us to adopt him because she was unable to care for him. Michael had been a failure to thrive baby, weighing 8 ½ lbs at 2 ½ months, with so much anxiety and stress that he could not hold eye contact with anyone. After taking him in, he began to gain weight and thrive.

Initially, there were no signs of any problems with Michael. He behaved as any normal infant would. It was not until he was 6 yrs old, in the first grade that I began to see that Michael had some problems. He had difficulty staying on task and paying attention, as well as problems following directions. He was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) at age 7. We did not start him on medication until the 3rd grade, because being a nurse, I wanted to try other ways to deal with the problem, but nothing worked. As he grew older, symptoms became worse. He could not organize his work (he could never find anything and his desk at school was a mess), he was unable to copy homework assignment or notes off the board, he always forgot to turn in homework, he was unable to take test because he could not sit long enough and concentrate, and his social skills were very poor. Well to be honest, he had no social skills. We struggled through 3rd grade and did fairly well academically until he reached fourth grade. His teacher told me that in fourth grade the students were responsible for everything and she would no longer write homework assignments for him or remind him to turn in his homework. He went from A's and B's to D's and F's within the first quarter of school.

As MCAH director, I had just began to work with Dr. Chasnoff, learning so much from him about FAS, when I became aware that Michael had many of the same behaviors as the FAS children he was working with. In December of 2003, we took Michael back to Chicago to the Children's Research Triangle to be tested. It was determined after 2 ½ days of testing, that Michael was FAS. I was devastated. When I went back to Chicago, I wanted Dr. Chasnoff to see Michael and tell me that nothing was wrong and to take Michael home and have a good life. Our lives had been changed forever.

The older Michael has gotten, the more difficult it has become. Maturity wise, he is about 4-5 years behind his chronological age, which is typical for children with FAS. When I see him with the boys he has gone thru grade school with, the difference in

maturity is so striking it breaks my heart. They are becoming young men, and Michael is still that little boy in a big boy's body. People look at him and expect him to "act his age". When he doesn't, they think he is a behavioral problem and treat him as such. He has no friends to speak of. He usually buys his friend. The first week of school, some boys told Michael that if he bought them all pizza, he could eat with them. Several times we would get calls from school because his lunch account was so low. He had spent \$70 in three weeks, buying food for other kids. Who, according to my husband would wait for him in the morning by the snack bar. He has stolen jewelry and money from us to give to girls and others at school so they would like him. He lies continually. Some times to look important to the other children, and many times because he can not pull information from his brain so he will make something up so he won't get in trouble. He is easily influenced by others to do things because he does not understand consequences to behavior, even though he can verbally tell you what might happen if he does something. He can not connect his behavior to the consequence at the time; due to the brain changes that have come about from the prenatal exposure to alcohol. In school, when he was unable to sit and do desk work for an hour, he was sent to sit outside the classroom because he was disturbing the others. Teachers would constantly get on Michael for chewing on pencils, pens, and eraser, taking these items away from him. FAS children can concentrate better when chewing or fidgeting with something. When Michael had an item taken away from him, he just found something else to chew or manipulate, which made the teachers mad.

He has behavioral regulation difficulty, so he can become very angry one minute and cry the next. He has difficulty following directions, talks constantly and very loudly, his self esteem is poor, he is very unorganized, can't recall things easily, has no ability to manage money, can not read body language from others and continues to do things even when people are upset about the behavior and tells him so. He is harassed by others, picked on, and made fun of. Even the adults won't tolerate him very long, even after they know about his disability. A teacher at the junior high where Michael goes asked him to be removed from a shop class the first day because he did not think he could trust Michael in the class. My son had waited all year for the shop class. When I told him that the teacher did not want him in the class, he began to cry and asked me what he had done. He had done nothing. The teacher had heard some thing about him and did not think Michael could be in the class without constant attention. He was labeled and not even given a chance to try and prove himself.

The social aspect of FAS is to me the most devastating. Michael thinks everyone is his friend, when in truth they don't like him at all. When he does meet some one it last maybe a day or two, then the other children don't want to be around him. He will beg children to come and play, call them on the phone and harass them about coming to his house or going to theirs. My biggest fear is that my son will become involved in a gang, where they will pretend to be his friend just to use him. He would not hesitate to do what ever they ask if it meant that they accepted him as one of them.

These are the types of things we deal with on a daily basis. It breaks my heart to see my son struggling everyday to just be accepted and to do well in school. It is so difficult for

him and us. Financially it has been rough because he needs so many services and many of them our insurance will not pay for. He sees a therapist, psychiatrist, and occupational therapist and is in group counseling. Emotionally, it is unbearable at times. It has caused problems in my husband and my relationship, in my extended family, my church, school and socially.

The most devastating things about all this is that it could have been prevented. My son's birth mother drank alcohol, smoked and used some methamphetamines during pregnancy. For me, the alcohol was the most devastating drug she could have used, because it did the most damage. Educating our mothers and supporting them to be substance free during pregnancy is little price to pay for giving a child a better life. We can't ignore what women are doing to themselves and their children. Their behavior is affecting all of us. Our prisons are full of these children. Schools can not keep up with the increasing numbers of children needing service. The judicial system is over run with these children as they become young adults. When do we finally step up and say enough is enough. We need to educate women and their families on the use of alcohol during pregnancy. And then support them and give them whatever intervention is necessary. We can not wait until these children are born to intervene. We need to make sure that they are given the best chance possible to develop normally and be healthy.

In San Luis Obispo County, we have begun to assess all pregnant women for alcohol, tobacco and other drug use during pregnancy. When we began this program in 2003, 51% of the women we assessed were positive for alcohol and/or tobacco use in the first trimester. Over the last four years, the OB providers in San Luis Obispo have been using the 4P's Plus assessment tool and the "I am concerned" brief intervention with great success. We have decreased our positive assessment percentage by almost half, to 27%. Most women, if they have the knowledge, will do what is best for themselves and their babies. FAS/FASD is 10 times more prominent than any other birth defect. The main difference between FAS/FASD and other birth defects is that it is 100% preventable. Our message is "NO AMOUNT OF ALCOHOL DURING PREGNANCY IS SAFE".

We need to step up to the plate and put monies into an area that we can make the most difference, before these children are exposed and brain changes are permanent. We spend billions to provide services for children and their families who are living with FAS/FASD. Our children are our future. If I can prevent one family from going through what my family has gone through, I feel I have made a difference. If we can make others realize what alcohol can do during pregnancy we can change thousands of lives for the better. Isn't that really what it is all about?